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ABSTRACT

The scope of this bibliography encompasses the social and psychological aspects of genetic disorders. The bibliography lists selected English-language articles and books from the professional literature along with audiovisual materials produced by both voluntary organizations and professional filmmakers. The entries are organized by the following topics: adoption, chromosomal anomalies, clergy involvement and pastoral care, coping, decision making, disabilities and chronic illness, education, ethical and legal issues, family dynamics, genetic counseling, genetic screening, mourning and grieving, prenatal diagnosis, siblings, social work intervention, specific disorders, and support groups. For each of the almost 500 items, the author, publication date, title, and other bibliographic information are provided. Appendices include an explanation of the computerized literature retrieval services of the National Library of Medicine, a description of selected databases available on the MEDLARS network, and a list of the seven Regional Medical Libraries across the United States which coordinate online search services with the National Library of Medicine. (JDD)

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SOCIAL AND PSYCHOLOGICAL ASPECTS OF GENETIC DISORDERS:

A Selected Bibliography

NCEMCH
National Center for Education in Maternal and Child Health

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PREFACE

Social and Psychological Aspects of Genetic Disorders is a selected bibliography of both articles and books from the professional literature, and audiovisual materials produced by voluntary organizations and professional filmmakers. The bibliography is not meant to be comprehensive. Inclusion in the bibliography does not imply endorsement of the information therein by the National Center for Education in Maternal and Child Health or by any of its sponsors. The bibliography is arranged by subject, with some materials listed under more than one heading. For rental and purchase costs of audiovisual materials, please contact the organization listed with each entry. For further information we suggest you explore the National Library of Medicine's MEDLARS/MEDLINE system. Local medical center libraries usually have access to this system. Lists of Regional Medical Libraries and of the databases available on the online networks are included at the end of the publication. The cost of services depends upon the institution performing the search. (See Appendices.) In addition, there are a number of non-medical online databases which can provide highly pertinent information, e.g., Psychological Abstracts and Sociological Abstracts. The Regional Medical Libraries as well as many public and academic libraries have access to these systems.

A number of people deserve acknowledgement for their assistance in the development and review of this update of the bibliography: Robert Arrindell, MSW, Genetic Diseases Services Branch, Division of Maternal and Child Health; Barbara Bernhardt, MS, Division of Medical Genetics, The Johns Hopkins Hospital; and Lynda Mulhauser, MSW, Children's Hospital National Medical Center; Candice Stevens, PhD, Osteogenesis Imperfecta Foundation, Inc., National Capital Area; Joan O. Weiss, MSW, ACSW, Division of Medical Genetics, The Johns Hopkins Hospital. We also appreciate the contribution of Janet Williams, RN, MA, Division of Medical Genetics, The University of Iowa and Peggy Heine, MSW, ACSW, Department of Pediatrics, University of Colorado Health Sciences Center to the publication.

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INTRODUCTION

In the past two decades the field of medical genetics has undergone rapid and dramatic change. Advances in medical science and technology have transformed a research-oriented academic field into a clinically useful, increasingly accessible medical specialty. The availability of carrier detection, prenatal diagnosis, and fetal treatment is increasing for a number of genetic conditions. In addition, accomplishments in genetic engineering provide hope for effective treatment of many genetic disorders.

As knowledge of these medical advances becomes widespread, an increasing number of individuals and their families who are at risk for or have a genetic disorder are requesting services. The process of helping the individual and family to understand and adjust to the unique problems associated with a genetic disorder requires special knowledge and skills. Health professionals must respond appropriately and deal with the potential disruption of family life and the alteration of life styles which these individuals and families may experience.

Social and psychological issues permeate every aspect of medical genetics. This bibliography is intended to assist health professionals to provide genetic services more effectively, and thus to contribute to better health care for mothers, children, and families.

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Audiovisuals (Disabilities and Chronic Illness)

Tell Them I'm A Mermaid
3/4" videocassette, 30 minutes

Osteogenesis Imperfecta Foundation, Inc.
National Capital Area
1311 Delaware Avenue, S.W.
Washington, DC 20024

Four disabled women discuss their experiences and coping strategies.

The Same Inside
3/4" videocassette, 1/2" videocassette, 16mm film, 13 minutes, color

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605
(914) 428-7100

Four special-needs children talk about their disabilities. This film is designed for children ages 5-11 but adults will also respond to the positive way that the children discuss their daily lives.

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Audiovisuals (Ethical and Legal Issues)

Frontline: Better Off Dead?
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A sensitive treatment of issues surrounding medical treatment for severely handicapped newborns. Parents and health professionals are interviewed.

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Audiovisuals (Family Dynamics)

Never Too Young
16 mm film, 15 minutes, color

United Cerebral Palsy Association, Inc.
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Presented by members of the immediate and extended families of atypical infants and persons from collaborating development centers. Shows a variety of ways parents can be involved.

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Audiovisuals (Genetic Screening)

Hard Choices - Genetic Screening: The Ultimate in Preventive Medicine
3/4" videocassette, 59 minutes, color

PBS Video
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Alexandria, VA 22314-1698
(703) 739-5000
(800) 344-3337

Explores the problems and options connected with genetic screening and examines how genetic screening and counseling have affected some individuals.

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Sammons CC (1978) Ethical issues in genetic intervention. Social work 23 (3): 237-242.

Silvestre D, Fresco N (1980) Reactions to prenatal diagnosis: analysis of 87 interviews. American Journal of Orthopsychiatry 50 (4): 610-617.

Verjaal M, Leschot NJ, Treffers PE (1982) Women's experiences with second trimester prenatal diagnosis. Prenatal Diagnosis 2 (3): 195-209.

Wright EE, Shaw MW (1981) Legal liability in genetic screening, genetic counseling, and prenatal diagnosis. Clinical Obsterics and Gynecology 24 (4) 1138-1146

Audiovisuals (Prenatal Diagnosis)

Hard Choices - Boy or Girl: Should the Choice Be Ours?
3/4" videocassette, 59 minutes, color

PBS Video
1320 Braddock Place
Alexandria, VA 22314-1968
(703) 739-5000
(800) 424-7964

Considers the effects of parents having a choice in determining the sex of their offspring and whether the decision should be theirs.

Questions in Prenatal Diagnosis: Bambi's Story
3/4" videocassette, 30 minutes, color
Central Conference Media Exchange

Cincinnati Center for Developmental Disorders
Elland and Bethesda Avenues
Cincinnati, OH
(513) 559-4760

Depicts the experiences of a young woman undergoing genetic counseling and prenatal diagnosis.

Support for Prenatal Decision
3/4" videocassette, 40 minutes, 30 seconds, color
Mobile Visual Productions, Inc.

Loma Linda University Medical Center
Division of Genetics
Room A-527
Loma Linda, CA 92350
(714) 796-7311

Couples discuss the decision making process involved in pregnancy termination for genetic indications.

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Crocker AC (1981) The involvement of siblings of children with handicaps. In: Milunsky A [ed] Coping with Crisis and Handicap. Plenum Press, New York, 219-228.

Grossman FK (1972) Brothers and Sisters of Retarded Children: An Exploratory Study. Syracuse University Press, New York.

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SOCIAL WORK INTERVENTION

Black RB (1981) Risk taking behavior: decision making in the face of genetic uncertainty. Social Work in Health Care 7(1): 11-25.

Black RB (1983) Genetics and adoption: a challenge for social work. In: Social Work in a Turbulent World. National Association of Social Workers, Silver Spring, MD.

Brantley D, West S (1983) The prevention of genetic disorders in underserved and rural areas. Human Services in the Rural Environment 8(1): 3-8.

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Finley BS, Crouthamel CS, Richman RA (1981) Psychosocial intervention program for children with short stature and their families. Social Work in Health Care 7(1): 27-35.

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Kern S (1981) Families of the developmentally disabled: helping models. In: Getty C, Humphreys W [eds] Understanding the Family: Stress and Change in American Family Life. Appleton-Century-Crofts, New York, 458-478.

Krush AJ (1982) Social work in research studies of families having hereditary cancer and precancer diagnoses. Social Work in Health Care 7(2): 39-48.

Oppenheimer JR, Rucker RW (1980) The effect of parental relationships on the management of cystic fibrosis and guidelines for social work intervention. Social Work in Health Care 5(4): 409-419.

Riehman L, Reichert B (1982) Social Work Practice: Meeting the Life Cycle Needs of Children and Youth with Handicapping Conditions. San Diego State University, San Diego, CA.

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SPECIFIC DISORDERS

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Cystic Fibrosis

Bywater EM (1981) Adolescents with cystic fibrosis: psychosocial adjustment. Archives of Disease in Childhood 56(7): 538-543.

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Drotar D (1978) Adaptational problems of children and adolescents with cystic fibrosis. Journal of Pediatric Psychology 3(1): 45-50.

Fischman SE (1979) Psychological issues in the genetic counseling of cystic fibrosis. In: Kessler S [ed] Genetic Counseling: Psychological Dimensions. Academic Press, New York, 153-165.

McCollum AT, Gibson LE (1970) Family adaptation to the child with cystic fibrosis. The Journal of Pediatrics 77(4): 571-578.

Oppenheimer JR, Rucker RW (1980) The effect of parental relationships on the management of cystic fibrosis and guidelines for social work intervention. Social Work in Health Care 5(4): 409-419.

Strauss GD, Wellisch DK (1981) Psychosocial adaptation in older cystic fibrosis patients. Journal of Chronic Diseases 34(4): 141-146.

Venters M (1981) Familial coping with chronic and severe childhood illness: the case of cystic fibrosis. Social Science and Medicine 15A: 289-297.

Audiovisuals (Cystic Fibrosis)

Living with Cystic Fibrosis
3/4" videocassette, 36 minutes, color

Cystic Fibrosis Foundation
6000 Executive Boulevard
Rockville, MD 20852
(301) 881-9130

Presents detailed information about the clinical features of cystic fibrosis. The mechanism of inheritance is discussed. Parents discuss their experiences.

The Story of Susan McKeller: Cystic Fibrosis
16 mm film, 3/4" videocassette, 20 minutes, color
Canadian Broadcasting Company

Filmakers Library, Inc.
133 East 58th Street
New York, NY 10022
(212) 355-6545

Winner of a blue ribbon at the 1982 American Film Festival, this film shows the daily life of a nurse who has cystic fibrosis. She presents her personal reactions and viewpoint concerning the disorder and its effect on her life.

Down Syndrome

Cunningham CC, Sloper T (1977) Parents of Down's syndrome babies: their early needs. Child: Care, Health and Development 3(5): 325-347.

Davis JH, Montgomery PA (1981) Adoption planning for handicapped children: a medical-social work partnership. Journal of Clinical Pediatrics 20(4): 292-294.

Dmitriev V (1983) A Time to Begin. Caring, Inc., Milton, WA.

Elkins TE, Anderson GD, Spinnato JA (1985) Helping parents adjust to Down's syndrome. Contemporary OB/GYN 25(3): 56-64.

Kirman B (1980) Growing up with Down's syndrome. British Journal of Hospital Medicine 23(4): 385-388.

Pueschel SM (1978) Down Syndrome: Growing and Learning. Andrews and McNeel, Inc., Mission, KS.

Audiovisuals (Down Syndrome)

David: A Portrait of a Retarded Youth
16 mm film, 3/4" videocassette, 28 minutes, color
Canadian Broadcasting Company

Filmakers Library, Inc.
133 East 58th Street
New York, NY 10022
(212) 355-6545

Winner of numerous awards, this film features David McFarlane, a 16-year-old with Down syndrome. David successfully played the lead in a television drama about Down Syndrome and won an international acting award. His efforts to memorize his lines, his relationship with the filming crew and his family are shown.

A Different Kind of Beginning
16 mm film, 9 minutes, color

The Association for Children With Down Syndrome, Inc.
Martin Avenue School
2616 Martin Avenue
Bellmore, NY 11710
(516) 221-4700

Shows an early intervention program. Very positive portrayal of the potential of Down syndrome children.

Gifts of Love
3/4", 1/2" videocassette, 53 minutes, color
Allstate Insurance Company

National Down Syndrome Society
141 Fifth Avenue, Suite 7S
New York, NY 10010
(212) 460-9330
(800) 221-4602

Four families of children with Down syndrome talk about their feelings and experiences.

Nancy and Scott: A Special Love
1/2" videocassette, 4 minutes, color

The Association for Children with Down Syndrome, Inc.
Martin Avenue School
2616 Martin Avenue
Bellmore, NY 11710
(516) 221-4700

Shows the loving relationship between a brother and his sister who has Down syndrome.

New Expectations
3/4", 1/2" videocassette, 13 minutes, color

National Association for Down's Syndrome
P.O. Box 4542
Oak Brook, IL 60521
(312) 325-9112

Highlights four persons with Down syndrome at various life stages (infant to adult). Parents are interviewed regarding their child's educational program, social activities, and vocational opportunities.

One of Our Own
16 mm film, 3/4" videocassette, 55 minutes, color
Canadian Broadcasting Company

Filmakers Library, Inc.
133 East 58th Street
New York, NY 10022
(212) 355-6545

A drama that pinpoints the problems of separation in a close-knit family, where one of the sons has Down syndrome. A move to a new community and the boy's approaching maturity cause the family to re-evaluate the wisdom of keeping him at home. The film stars David McFarlane, who has Down syndrome.

You Don't Outgrow Down Syndrome: Counseling Parents
3/4", 1/2" videocassette, slides and audiocassette, 18 minutes, color
Filmmedia Limited

National Association for Down Syndrome
P.O. Box 4542
Oak Brook, IL 60521
(312) 325-9112

Alerts physicians and hospital personnel to the urgent need for information and support of parents who have delivered a newborn with Down syndrome. Parents of children with Down syndrome recount how physicians told them of their child's condition and their subsequent reactions, fears, and thoughts. Physicians voice some of the problems and difficulties they encounter in this situation. The use of parent support groups is strongly advocated. Winner of second prize in the International Rehabilitation Film Festival, Filmstrip/Slide/Tape category.

Duchenne Muscular Dystrophy

Bregman AM (1980) Living with progressive childhood illness: parental management of neuromuscular disease. Social Work in Health Care 5(4): 387-407.

Lubs M (1979) Carrier screening in hemophilia and Duchenne muscular dystrophy: economic and psychological consequences. In: Porter IH, Hook EB [eds] Service and Education in Genetics. Academic Press, New York.

Fabry Disease

Sorensen SA, Hasholt L (1983) Attitudes of persons at risk for Fabry's disease towards predictive tests and genetic counselling. Journal of Biosocial Science 15(2): 89-94.

Fetal Alcohol Syndrome

Wright JM (1981) Fetal alcohol syndrome: the social work connection. Health and Social Work 6(1): 5-10.

Gaucher Disease

Gaucher's Disease: Coping, Caring and Searching for a Cure
3/4" videocassette, 21 minutes, color

National Gaucher Foundation, Inc.
1424 K Street, N.W.
Washington, DC 20005
(202) 393-2777

Discusses clinical and genetics aspects of Gaucher disease as well as current research. Several interviews with patients and families are featured.

Hemophilia

Hemophilia: A Bibliography of Mental Health and Social Service References (1983) National Hemophilia Foundation, Mental Health Committee, New York.

Lubs M (1979) Carrier screening in hemophilia and Duchenne muscular dystrophy: economic and psychological consequences. In: Porter IH, Hook EB [eds] Service and Education in Genetics. Academic Press, New York.

Markova I, Forbes CD (1984) Coping with haemophilia. International Review of Applied Psychology 33(4): 457-477.

Markova I, MacDonald K, Forbes C (1980) Impact of haemophilia on childrearing practices and parental co-operation. Journal of Child Psychology and Psychiatry 21(2): 153-162.

Psychological and Social Components of Comprehensive Care for Persons with Hemophilia and Their Families (1981) DHHS pub. no. (HSA) 81-5247A.

Reis E, Linhart R, Lazerson J (1982) Using a standard form to collect psychosocial data about hemophilia patients. Health and Social Work 7(3): 206-214.

Audiovisuals (Hemophilia)

Through the Genetic Maze: A 50/50 Chance
3/4" videocassette, 58 minutes, color
Pennsylvania State University

PBS Video
1320 Braddock Place
Alexandria, VA 22314-1698
(703) 739-5000
(800) 344-3337

Discusses X-linked inheritance with hemophilia as a model. Interviews parents and patients. Discusses the option of prenatal diagnosis.

Hunter Syndrome

Young ID, Harper PS (1981) Psychosocial problems in Hunter's syndrome. Child: Care, Health and Development 7(4): 201-209.

Huntington Disease

Falek A, Britten S (1974) Phases in coping: the hypothesis and its implications. Social Biology 21(1): 1-7.

Folstein SE, Franz ML, Jensen BA, Chase GA, Folstein MF (1983) Conduct disorder and affective disorder among the offspring of patients with Huntington's disease. Psychological Medicine 13(1): 45-52.

Hans MB, Koeppen AH (1980) Huntington's chorea: its impact on the spouse. The Journal of Nervous and Mental Disease 168(4): 209-214.

Johnston R, Seitz K (1981) Policy choices available in genetic counseling for people at-risk for Huntington disease. Psychiatric Quarterly 53(3): 194-200.

McCormack MK, Leiblum S, Lazzarini A (1983) Attitudes regarding utilization of artificial insemination by donor in Huntington disease. American Journal of Medical Genetics 14(1): 5-13.

Miller E (1976) The social work component in community-based action on behalf of victims of Huntington's disease. Social Work in Health Care 2(1): 25-32.

Rosenfeld A (1984) At risk for Huntington's disease: who should know what and when? The Hastings Center Report 14(3): 5-8.

Schoenfeld M, Berkman B, Myers RH, Clark E (1984) Attitudes toward marriage and childbearing of individuals at risk for Huntington's disease. Social Work in Health Care 9(4): 73-81.

Wexler N (1979) Perceptual-motor, cognitive and emotional characteristics of persons at risk for Huntington's disease. In: Chase TM, Wexler NS, Barbeau A [eds] Advances in Neurology 23. Raven Press, New York, 257-271.

Immune Deficiency Syndrome

Moment to Moment
1/2" videocassette, 23 minutes, color
Sheffield Audio-Video Productions

Immune Deficiency Foundation
P.O. Box 586
Columbia, MD 21045
(301) 461-3127

Gives an overview of the body's immune system and describes the variety of immune deficiency diseases. Patients and their families discuss their experiences.

Klinefelter Syndrome

Plumridge D, Barkost C, Lafranchi S (1982) Klinefelter Syndrome: The X-tra Special Boy. University of Oregon Health Sciences Center, Portland, OR.

Walzer S, Wolff PH, Bowen D, Silbert AR, Bashir AS, Gerald PS, Richmond JB (1977) A method for the longitudinal study of behavioral development in infants and children: the early development of XXY children. Journal of Child Psychology and Psychiatry 19(3): 213-229.

Neurofibromatosis

Riccardi V (1982) Early manifestations of neurofibromatosis: diagnosis and management. Comprehensive Therapy 8(10): 35-40.

Stephenson C (1982) Diagnosing and dealing with neurofibromatosis in children. The American Journal of Maternal-Child Nursing 7(6): 387-390.

Osteogenesis Imperfecta

Kiely L, Sterne RT, Witkop CJ (1976) Psychosocial factors in low-incidence genetic disease: the case of osteogenesis imperfecta. Social Work in Health Care 1(4): 409-420.

Audiovisuals (Osteogenesis Imperfecta)

Brittle Bones
16 mm film, 21 minutes, color
Film in the Cities

American Brittle Bone Society
1256 Merrill Drive
West Chester, PA 19380
(215) 692-6248

Depicts a number of people with osteogenesis imperfecta. Their struggles to cope with the disease, as well as their families' involvement are documented. The film also contains information about treatment and research.

Phenylketonuria (PKU)

Barnico LM, Cullinane MM (1985) Maternal phenylketonuria: an unexpected challenge. The American Journal of Maternal-Child Nursing 10(2): 108-110.

Levy HL (1982) Maternal PKU: control of an emerging problem. American Journal of Public Health 72(12): 1320-1321.

Pueschel SM, Yeatman S (1977) An educational and counseling program for phenylketonuric adolescent girls and their parents. Social Work in Health Care 3(1): 29-36.

Schild S (1979) Psychological issues in genetic counseling of phenylketonuria. In: Kessler S [ed] Genetic Counseling: Psychological Dimensions, Academic Press, New York, 135-152.

Polycystic Kidney Disease

Sahney S, Weiss L, Levin NW (1982) Genetic counseling in adult polycystic kidney disease. American Journal of Medical Genetics 11(4): 461-468.

Porphyria

Porphyria: An Introduction
3/4", 1/2" videocassette, 30 minutes, color
Health and Science Network

American Porphyria Foundation Tape
901 Hillgrove
La Grange, IL 60525

Leading porphyria specialists and researchers discuss the origin of the disease, its symptoms, and its diagnosis and treatment, while patients discuss how they have been affected by the disorder.

Prader-Willi Syndrome

Oakwood Residence: A Home for Prader-Willi People
1/2" videocassette, 36 minutes, color

Prader-Willi Syndrome Association
5515 Malibu Drive
Edina, MN 55436
(612) 933-0113

Documents the efforts of the Prader-Willi Syndrome Association to establish a group home for persons with Prader-Willi Syndrome. Residents of the home are interviewed. Staff members also discuss their roles in modifying the behavior of the Prader-Willi individuals who reside at Oakwood.

Prader-Willi Syndrome
60 slides and audiocassette

Prader-Willi Syndrome Association
5515 Malibu Drive
Edina, MN 55436
(612) 933-0113

Discusses various clinical aspects of the Prader-Willi syndrome and the work of the Prader-Willi Association.

Short Stature

Ablon J (1982) The parents' auxiliary of Little People of America: a self-help model of social support for families of short statured children. Prevention in Human Services 1(3): 31-46.

Ablon J (1984) Little People in America: The Social Dimensions of Dwarfism. Praeger Publishers, New York.

Brust JS, Ford CU, Rimoin DL (1976) Psychiatric aspects of dwarfism. American Journal of Psychiatry 133(2): 160-164.

Finley BS, Crouthamel CS, Richman RA (1981) Psychosocial intervention program for children with short stature and their families. Social Work in Health Care 7(1): 27-35.

Plumridge D (1976) Good Things Come in Small Packages: The Whys and Hows of Turner's Syndrome. University of Oregon Health Sciences Center, Portland, OR.

Rogers JG, Weiss JO (1977) My Child is a Dwarf. Little People of America Foundation, Owatonna, MN.

Audiovisuals (Short Stature)

Little People
3/4" videocassette, 60 minutes, color
Little People of America, Inc.

Filmakers Library, Inc.
133 East 58th Street
New York, NY 10022
(212) 355-6545

A positive account of the experiences and feelings of members of the Little People of America.

Sickle Cell Anemia

Conyard S, Krishnamurthy M, Dosik H (1980) Psychological aspects of sickle cell anemia in adolescents. Health and Social Work 5(10): 20-26.

Headings VE (1979) Psychological issues in sickle cell counseling. In: Kessler S [ed] Genetic Counseling: Psychological Dimensions, Academic Press, New York, 185-198.

Whitten CF, Fischhoff J (1974) Psychosocial effects of sickle cell disease. Archives of Internal Medicine 133(4): 681-689.

Whitten CF, Thomas JF, Nishiura EN (1981) Sickle cell trait counseling--evaluation of counselors and counselees. American Journal of Human Genetics 33(5): 802-816.

Audiovisuals (Sickle Cell Anemia)

Living with Hope
3/4" videocassette, 21 minutes, color

Sickle Cell Anemia Research and Education, Inc.
330 41st Street
Oakland, CA 94609
(415) 547-6965

Discusses sickle cell anemia and sickle cell trait through interviews with parents, patients, and health care professionals.

Sickle Cell Anemia
3/4" videocassette, 16 mm film, 22 minutes, color
Canadian Broadcasting Company

Filmakers Library, Inc.
133 East 58th Street
New York, NY 10022
(212) 355-6545

Deals with sickle cell anemia on a scientific and human level. Features interviews with members of a family in which there are three affected children.

Spina Bifida

Blum R (1983) The adolescent with spina bifida. Clinical Pediatrics 22(5): 331-335.

The Child with Spina Bifida, (II): Psychological, Educational, and Family Concerns (1982) Clinical Proceedings: Children's Hospital National Medical Center 38(4), Washington, DC, 189-236.

Darling RB (1977) Parents, physicians, and spina bifida. The Hastings Center Report 7(4): 10-14.

Feldman WS, Varni JW (1985) Conceptualizations of health and illness by children with spina bifida. Child Health Care 13(3): 102-108.

Goldstein SB (1980) The effect of mainstreaming on self-esteem in adolescents and young adults with spina bifida. Spina Bifida Therapy 2(4): 309-319.

Hayden PW, Davenport SLH, Campbell MM (1979) Adolescents with myelodysplasia: impact of physical disability on emotional maturation. Pediatrics 64(1): 53-59.

Laurence KM, Morris J (1981) The effect of the introduction of prenatal diagnosis on the reproductive history of women at increased risk from neural tube defects. Prenatal Diagnosis 1(1): 51-60.

Audiovisuals (Spina Bifida)

A Handicapped Child - A Family in Crisis
Filmstrip and audiocassette

Spina Bifida Association of America
343 South Dearborn Street
Chicago, IL 60604
(312) 663-1562

A family of two adults and four children discuss their experiences and feelings when a son is born with spina bifida. Winner of a Peabody Award.

Hope for the Future
Slides and audiocassette

Spina Bifida Association of America
343 South Dearborn Street
Chicago, IL 60604
(312) 663-1562

Explains the Spina Bifida Association of America and its goals for the future. Narrated by Phil Donahue.

I'll Find a Way
16 mm film, 26 minutes, color

Spina Bifida Association of America
343 South Dearborn Street
Chicago, IL 60604
(312) 663-1562

Nadia De Franco, a nine-year-old with spina bifida, narrates this film and introduces her family and friends. 1978 Academy Award winner for best picture; live action short subject.

Ordinary People - Special Needs
Slides and audiocassette

Spina Bifida Association of America
343 South Dearborn Street
Chicago, IL 60604
(312) 663-1562

Shows the potential of individuals with spina bifida. Narrated by Phil Donahue.

Tay-Sachs Disease

Childs B, Gordis L, Kaback MM, Kazazian HH (1976) Tay-Sachs screening: social and psychological impact. American Journal of Human Genetics 28(6): 550-558.

Goodman MJ, Goodman LE (1982) The overselling of genetic anxiety. The Hastings Center Report 12(5): 20-27.

Paritzky JF (1985) Tay-Sachs: the dreaded inheritance. American Journal of Nursing 85(3): 260-264.

Audiovisuals (Tay-Sachs Disease)

Through the Genetic Maze - A Two-Edged Sword
3/4" videocassette, 58 minutes, color

PBS Video
1320 Braddock Place
Alexandria, VA 22314-1698
(703) 739-5000
(800) 344-3337

Focuses on carrier detection and prenatal diagnosis of Tay-Sachs disease.

Thalassemia

Kim SP (1978) Group meetings with parents of children with Cooley's anemia. Journal of the American Society of Psychosomatic Dentistry and Medicine 25(1): 12-19.

Modell B, Ward RHT, Fairweather DVJ (1980) Effect of introducing antenatal diagnosis on reproductive behaviour of families at risk for thalassemia major. British Medical Journal 280: 1347-1350.

Tsiantis J, Xypolita-Tsantili D, Papadakou-Lagoyianni S (1982) Family reactions and their management in a parents group with beta-thalassemia. Archives of Disease in Childhood 57(11): 860-863.

Turner Syndrome

Plumridge D (1976) Good Things Come in Small Packages: The Whys and Hows of Turner's Syndrome. University of Oregon Health Sciences Center, Portland, OR.

Audiovisuals (Turner Syndrome)

Turner Syndrome
3/4" videocassette, 30 minutes, color

Turner Syndrome Society
Administrative Studies
Building #006
York University
4700 Keele Street
Downsview, Ontario M3J IP3
Canada
(416) 667-3773

A thorough discussion of the clinical and psychological aspects and genetics of Turner syndrome is presented by an endocrinologist, a gynecologist, a psychologist and a cytogeneticist. Groups of women with Turner syndrome discuss various aspects of their lives. Parents share methods of coping. Public awareness activities of the Turner Syndrome Society are described.

Werdnig-Hoffmann Disease

Bregman AM (1980) Living with progressive childhood illness: parental management of neuromuscular disease. Social Work in Health Care 5(4): 387-407.

S U P P O R T G R O U P S

Ablon J (1982) The parents' auxiliary of Little People of America: a self-help model of social support for families of short-statured children. Prevention in Human Services 1(3): 31-46.

Finley BS, Crouthamel CS, Richman RA (1981) Psychosocial intervention program for children with short stature and their families. Social Work in Health Care 7(1): 27-35.

Fischhoff J, O'Brien N (1976) After the child dies. Journal of Pediatrics 88(1): 140-146.

Haffner D (1980) Learning Together: A Guide for Families with Genetic Disorders. DHHS pub. no. (HSA) 80-5131.

Humm A (1979) How to Organize a Self-Help Group. New York City Self-Help Clearinghouse, New York.

Miller E (1976) The social work component in community-based action on behalf of victims of Huntington's disease. Social Work in Health Care 2(1): 25-32.

Pueschel SM, Yeatman S (1977) An educational and counseling program for phenylketonuric adolescent girls and their parents. Social Work in Health Care 3(1): 29-36.

Saunders AM, Lamb W (1977) A group experience with parents of hemophiliacs: a viable alternative to group therapy. Journal of Clinical Child Psychology 6(3): 79-82.

APPENDIX A

COMPUTERIZED LITERATURE RETRIEVAL SERVICES OF THE NATIONAL LIBRARY OF MEDICINE

Those studying or working in the health sciences have access to the professional literature through a computerized system known as MEDLARS (Medical Literature Analysis and Retrieval System). Based at the National Library of Medicine (NLM) in Bethesda, Maryland, MEDLARS is available through a nationwide network of online centers at more than 2500 universities, medical schools, hospitals, government agencies, and commercial organizations.

MEDLARS contains some 8,000,000 references to journals, articles, and books published after 1965. Most of these references have been published in Index Medicus, or in other printed indexes and bibliographies. The computer system makes it possible to search online for references pertinent to a specific question.

There are a number of databases available through the online network. Some are described in Appendix B, including MEDLINE (MEDLARS Online), the largest and most frequently used.

Terminals at each of the network institutions are connected via commercial telephone lines to NLM's computers. To retrieve references, a user carries on a "dialog" with the computer refining the search by typing successive queries until the needed references are identified.

Information can be retrieved by searching for combinations of the 14,000 Medical Subject Headings (MeSH) and over 41,000 chemical substances used by NLM to index and catalog materials. It is also possible to search by using words appearing in the titles or abstracts of the references. The computer's ability to search rapidly results in individualized bibliographies that would be difficult to compile by searching printed indexes.

The user may ask that complete "records" be printed, including a full bibliographic citation, subject headings, and abstracts (where available). It is also possible to print abbreviated citations, such as author, title, and source.

Articles or books identified by searching MEDLARS may be requested through the online center's library. Requests for items not available locally are routed through a system of seven Regional Medical Libraries (see Appendix C). NLM provides loans of materials that are not available in local regional libraries.

The fees for online services vary among online centers. Some absorb all or most of the costs; others charge a modest fee for staff time and for time connected to NLM's computer, as well as NLM's charges for offline printing of bibliographies.

APPENDIX B

SELECTED DATABASES AVAILABLE ON THE MEDLARS NETWORK

AVLINE (Audiovisuals Online) contains citations to over 14,000 audiovisual teaching packages covering a wide range of subject areas in medicine, dentistry, nursing, allied health, and other disciplines. In some cases, descriptive review information such as rating, audience levels, instructional design, specialties, and abstracts is included. Procurement information on titles is provided.

BIOETHICSLINE contains bibliographic citations to documents which discuss ethical questions arising in health care or biomedical research. It is a comprehensive, cross-disciplinary collection of references to both print and nonprint materials. Among the publication types included in the database are journal and newspaper articles, monographs, analytics, court decisions, and audiovisual materials. The database contains over 19,000 citations from 1973 to date. Citations in BIOETHICSLINE appear also in the Bibliography of Bioethics, an annual publication of the Center for Bioethics, Kennedy Institute of Ethics, Georgetown University.

CATLINE (Catalog Online) contains about 600,000 references to books and serials catalogued at NLM. CATLINE gives medical libraries in the network immediate access to authoritative cataloging information and thus reduces the need for these libraries to do their own original cataloging. Libraries also find this database a useful source of information for ordering books and journals and for providing reference and interlibrary loan services.

DIRLINE (Directory of Information Resources Online) contains information on over 15,000 resource centers and can be used as a referral service to locate information not readily obtainable from the bibliographic or factual databases. Included in each record is the organization name, address, scope of coverage, and types of services provided. The file is updated quarterly.

MEDLINE contains approximately 800,000 references to biomedical journal articles published in the current and preceding three years. An English abstract, if published with the article, is included. The articles are from 3200 journals published in the United States and in foreign countries. Coverage of previous periods (back to 1966) is provided by backfiles totaling some 5,000,000 references and searchable online.

MEDLINE can also be used to update a search periodically. The search formulation is stored in the computer and each month, when new references are added to the database, the search is processed automatically and the results mailed from NLM.

POPLINE (Population Information Online) is a bibliographic database citing the literature in the areas of family planning, fertility control, population and reproduction. The POPLINE file contains citations and abstracts to a variety of materials including journal articles, monographs, technical reports, and unpublished works. POPLINE currently contains approximately 133,000 citations. The majority of the items were published from 1970 to the present, but there are selected citations dating back to 1886. The database increases by about 10,000 citations annually and is updated monthly.

SERLINE (Serials Online) contains bibliographic information for about 60,000 serial titles, including all journals which are on order or cataloged for the NLM collection. For many of these, SERLINE has locator information for the user to determine which United States medical libraries own a particular journal. SERLINE is used by librarians to obtain information needed to order journals and to refer interlibrary loan requests.

TOXLINE (Toxicology Information Online) is a bibliographic database of over 1.7 million references covering the pharmacological, biochemical, physiological, environmental, and toxicological effects of drugs and other chemicals. Almost all references in TOXLINE have abstracts and/or indexing terms and Chemical Abstracts Service (CAS) Registry Numbers.

APPENDIX C

REGIONAL MEDICAL LIBRARIES

Seven Regional Medical Libraries, each responsible for a geographic area, coordinate NLM's online search services in the United States. These libraries also handle requests for health literature not available locally, and pass on to the NLM requests they cannot fill. To find out the nearest online center, or how your institution can become a center, write to the Regional Medical Library for your area.

Region I

Greater Northeastern Regional Medical Library Program
(CT, DE, MA, ME, NH, NJ, NY, PA, RI, VT, and Puerto Rico)
The New York Academy of Medicine
2 East 103rd Street (212) 876-8763
New York, NY 10029

Region II

Southeastern/Atlantic Regional Medical Library Services (STARS)
(AL, DC, FL, GA, MD, MS, NC, SC, TN, VA, WV and the Virgin Islands)
University of Maryland
Health Sciences Library (301) 528-2855
111 South Greene Street (800) 638-6093 outside MD
Baltimore, MD 21201

Region III

Greater Midwest Regional Medical Library Network
(IA, IL, IN, KY, MI, MN, ND, OH, SD, WI)
University of Illinois at Chicago
Library of the Health Sciences (312) 996-2464
P.O. Box 7509
Health Sciences Center
Chicago, IL 60680

Region IV

Midcontinental Regional Medical Library Program (MCRML)
(CO, KS, MO, NE, UT, WY)
University of Nebraska (402) 559-4326
Medical Center Library (800) MED-RML4
42nd and Dewey Avenue
Omaha, NE 68105-1065

Region V

South Central Regional Medical Library Program (TALON)
(AR, LA, NM, OK, TX)
University of Texas (214) 688-2085
Health Science Center at Dallas
5323 Harry Hines Boulevard
Dallas, TX 75235

Region VI	Pacific Northwest Regional Health Sciences Library Service (PNRHSLS) (AK, ID, MT, OR, WA) Health Sciences Library University of Washington Seattle, WA 98195	(206) 543-8262
Region VII	Pacific Southwest Regional Medical Library Service (PSRMLS) (AZ, CA, HI, NV, and U.S. Territories in the Pacific Basin) UCLA Biomedical Library Center for the Health Sciences Los Angeles, CA 90024	(213) 825-1200

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